

# **KORA-gen: 3 years of biobanking experience in Germany**

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# Content

- The KORA study and its use for genetic research
- KORA-gen – a population based biobank from Southern Germany
- Other epidemiological cohorts in Germany
- Ethics and biobanking
- Possible perspectives



# **KORA Augsburg**

## **An ongoing epidemiological study**

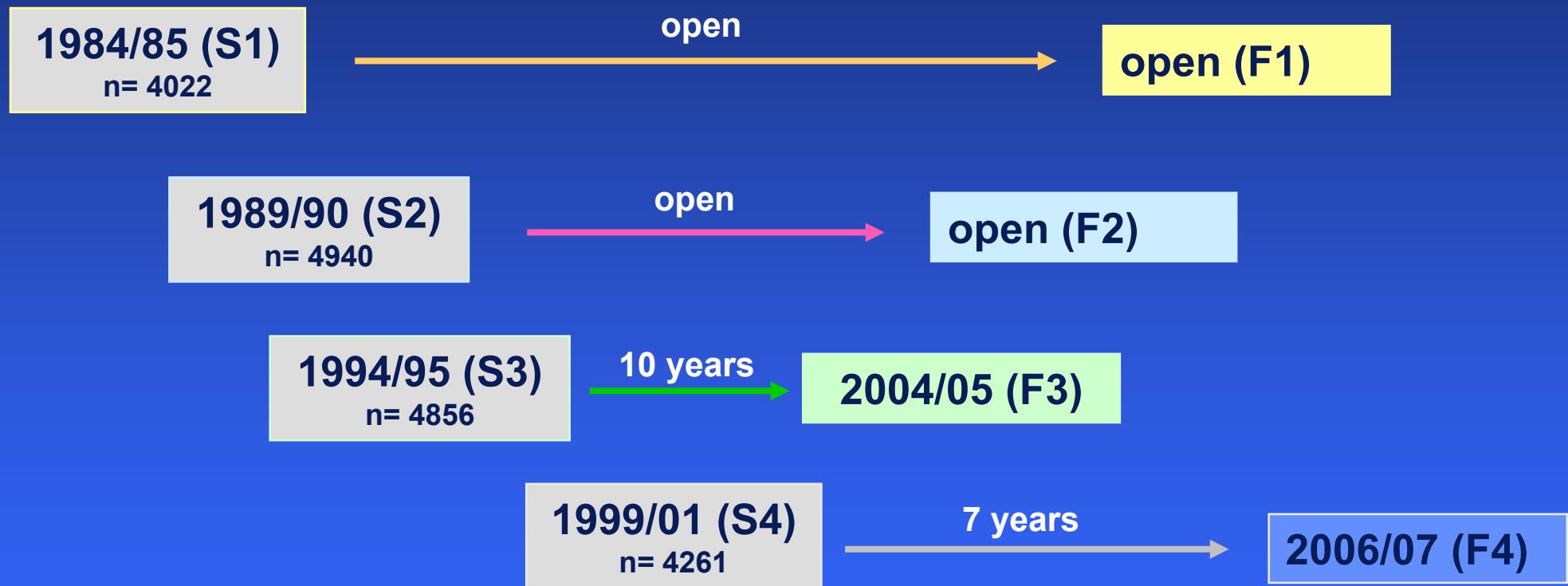
- **KORA**
  - = Kooperative Gesundheitsforschung in der Region Augsburg
  - = Cooperative Health Research in the Region of Augsburg
- Population based cohort study (18 000 individuals)
- Age range 25-74 years at recruitment
- Follow up investigations in regular intervals
- Study center open whole year



# KORA Augsburg

## An ongoing epidemiological study

1985 ..... KORA Myocardial Infarction Registry ..... → 2007



1985 → Biological Specimen Banking → 2007



GSF KORA Studienzentrum  
Viktoriastr. 3, 86150 Augsburg



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# KORA Augsburg

- **Information on multiple parameters available for**
  - **Sociodemography**
  - **Environmental factors, nutrition, smoking**
  - **General medical history : diseases, medication**
  - **Laboratory values of relevance to the disease fields**
- **Phenotyping of health related parameters for**
  - **Cardiovascular diseases**
  - **Metabolic disease, type 2 diabetes**
  - **Allergies**
  - **Cancer**



# KORA Augsburg

## Available phenotypic information

- Availability

	n	K/S	S1	S2	S3	S4
- Core Information	18 000	K	X	X	X	X
- ECG	13 000	K	X	X	-	X
- ECHO	1 600	S	X	-	X	-
- Glucose tolerance	1 700	K	-	-	-	X
- Sonography	1 400	S	-	X	-	-
- Atopy (spec. IgE)	8 000	K	-	-	X	X
- Lipid parameters	18 000	K	X	X	X	X
- Hemostaseology	13 000	S	X	-	X	X

K : KORA Core     S : Participation of topic related specialists



# KORA Augsburg

## Population-based genetic resource

- Population based prevalences of
  - Diseases
  - Binary traits / dichotomous phenotypes
- Population based reference values for
  - Quantitative traits
- Available resources for molecular genetics
  - DNA and serum samples from n = 18 000
  - Lymphoblastoid cell lines from n = 1 600



# KORA Augsburg population-based genetic resource

## Advantages

- Prospective accumulation of genetic and phenotypic information from the same individuals
- Platform design for multiple use and multiple contributions by different collaborators
- Anonymized database easily accessible



# KORA used as control population (examples)

- Bipolar affective disorders, Bonn
- Myocardial infarction, Ulm
- Chronic inflammatory diseases, Ulm
- Diabetic nephropathy, Regensburg
- Sporadic CJD, Munich
- Atrial arrhythmia, Munich
- Asthma, Munich



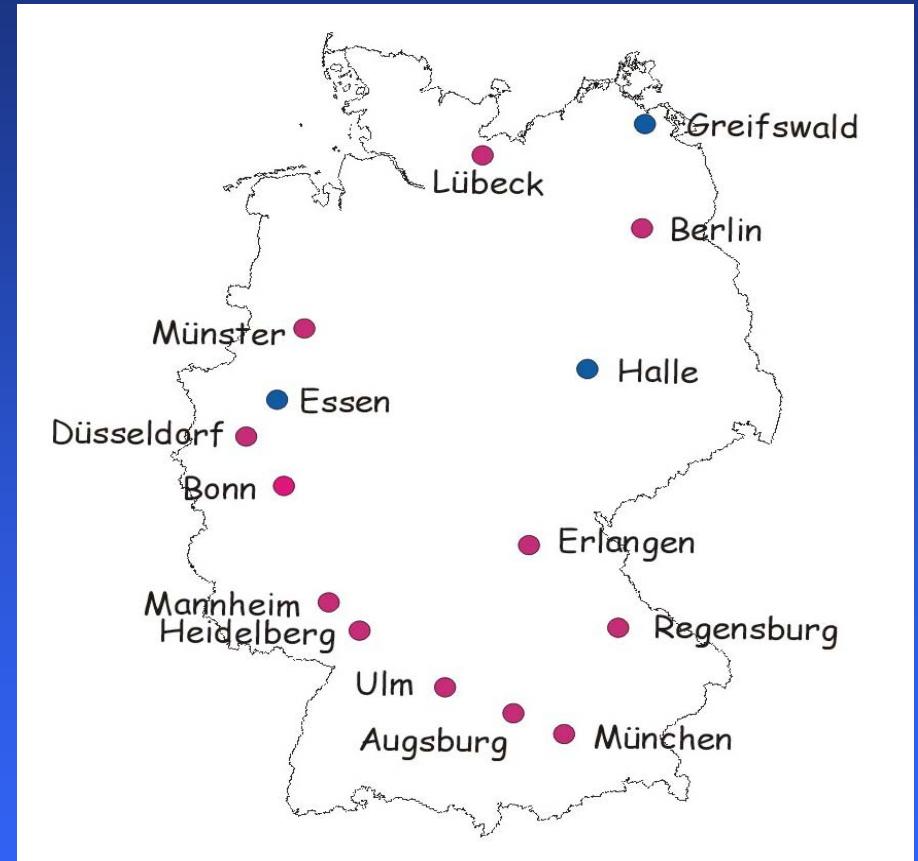
# KORA used as control population continued

- Breast cancer, Bonn/Heidelberg
- Lung cancer, Munich/Göttingen
- Parkinson's disease, Munich
- Alzheimer's disease, Munich
- Affective disorders, Munich



# KORA Partners in Germany

- Universities and Research Centers
- Cooperation with other population-based studies



# Databases in KORA

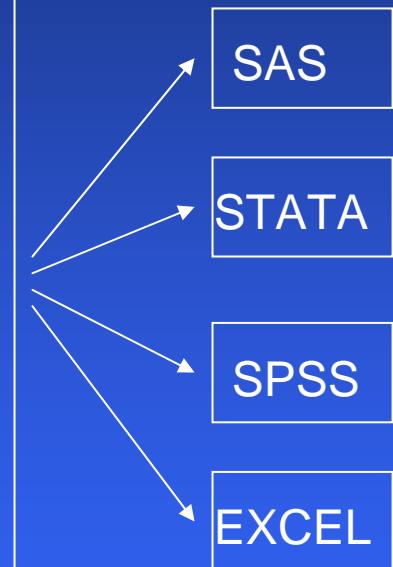
## data sources



## INGRES-DB

18 000 probands  
> 15 studies  
> 20 data owners  
> 100 Tables  
> 10 000 Variables

## data for analysis



# KORA: Data storage

- Separation of raw data and data for analysis
- Uniform concept for names of tables and variables
- Clearly defined access of users
- Comprehensive electronic documentation (Intranet)
- Study manuals and SOPs
- Comprehensive back-up system



# KORA: Genetic Resource

- KORA-Biobank
- resource for genetic analyses
  - DNA, serum n = 18 000
  - cell lines n = 1 600
- SNP-Analysis in Genome Analysis Center possible



# KORA probands with risk factors (4 surveys)

<b>hypertension (RR &gt; 140/90 mm Hg)</b>	<b>6 000</b>
<b>obesity (BMI <math>\geq</math> 30 kg/m<sup>2</sup>)</b>	<b>3 500</b>
<b>hypercholesterinemia (Chol. <math>\geq</math> 250)</b>	<b>5 600</b>
<b>active smokers</b>	<b>4 800</b>
<b>ex-smokers</b>	<b>5 100</b>



# KORA phenotypes (4 surveys)

alive	16 000
dead	1 600
Diabetes	1 800
Cancer	1 500
Myocardial infarction < 75 years	800



# KORA-gen: Biobank from Southern Germany

- expanding from S4 survey to earlier surveys
- rules for use of the resource
- rights of „old“ data owners
- how to avoid conflict when research interests overlap
- ethics and confidentiality for the old surveys  
(without explicit consent for genetic research)



# KORA-gen: study population

**n = 18 000**

	S1	S2	S3	S4
males	2023	2482	2405	2090
females	1999	2458	2451	2171



# KORA-gen: possibilities and limitations

- **Data (phenotypes, environmental parameters etc)**
  - Selected set of variables available for everybody
  - Other variables only with agreement of the data owners
- **Biosamples (DNA, serum, plasma, urine)**
  - available for everybody as long as enough is available
  - restrictions if samples are limited
- **Genotypes**
  - in a common data base
  - after few months available for everybody



# KORA-gen: Organisation

## Team

- **Scientific head**
- **Documentalist**
- **Additional expertise available for epidemiology, biostatistics, medical informatics, molecular biology**



# **KORA-gen: How to use it**

- Application (research question, variables and biosamples needed, genotyping, ethics, collaborators, coauthors for publication)
- Pre-evaluation/counseling by KORA team leader
- Evaluation by advisory board
- After acceptance: data/material transfer agreement
- Agreement of user, to provide the genotypes for the common pool



# Epidemiologic population cohorts in Germany (with public funding)

	n	follow-up
• KORA Augsburg	18 000	5-20y
• SHIP Greifswald	7 000	5y
• RECALL Essen	7 000	3y
• EPIC Potsdam	25 000	8y
• EPIC Heidelberg	25 000	8y
Sum	> 80 000	
• POPGEN Schleswig	patients	15 000
	controls	10 000



# Collections of patients in Germany (with public funding)

National competence networks (number of diseases)

cardiovascular (3)

infections (4)

neurological/ psychiatric (5)

cancer (3)

others (2)

Sum 17 diseases

Most have DNA banks



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# National German Ethics Board

Recommendation of 17 March 2004:

- Unlimited storage
- Consent without specification of research question
- Scientific use of 'old' samples
- Use of anonymized data and biological samples without informed consent

is possible under reasonable conditions



# **Biobanking**

## **– possible perspectives for Germany**

- **Big new biobank with public money: probably not**
- **Network of existing epidemiologic cohorts: possible**
- **Network of existing patient collections: possible**
- **New local activities: probable**



# Acknowledgements

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*KORA team Munich*

*KORA team Augsburg*

*KORA-gen team*

